The Children with Special Health Care Needs Services Program Transition Toolkit: *Improving Transition Outcomes in Texas*

Manda Hall, MD and **Rachel Jew,** Children with Special Health Care Needs (CSHCN) Services Program, Texas Department of State Health Services (DSHS)

Issue and Setting

Most youth with chronic illnesses will survive into adulthood and, depending on the severity and specifics of their disability, should transition to an adult model of care[1]. Healthy People 2020 has established the objective to increase the proportion of youth with special health care needs whose health care providers have discussed transition from pediatric to adult care[2]. According to the National Survey of Children with Special Health Care Needs 2009-2010, the outcome that youth with special health care needs receive the services necessary to make the transition to adult health care was achieved 40% of the time nationally and in Texas this standard was met for 35.4% of youth[3].

In 2002, the American Academy of Pediatrics, American Academy of Family Physicians and the American College of Physicians - American Society of Internal Medicine published *A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs* which sets the goal of transition to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. According to this policy, the central rationale for health care transition planning for young people with special health care needs is to achieve this goal by ensuring that adults receive primary medical care from those trained to provide it[4].

In the summer of 2013, a Graduate Student Epidemiology Program (GSEP) intern conducted a project at DSHS addressing Texas' Performance on the delivery of transition services for CSHCN.[5] She developed a Transition Questionnaire to inquire about current state policies and implementation of transition services; then compared Texas to the highest performing states (Kansas and Utah) and states demographically similar to Texas (California and Florida). All states completed the transition questionnaire except Florida. Results of the study include:

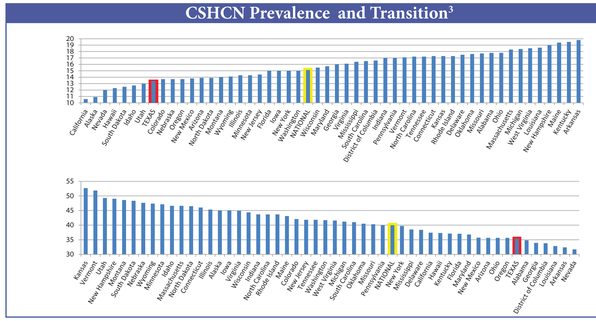
Major Findings:

- Across all states CSHCN who do not have a medical home are less likely to receive satisfactory transition services; CSHCN in Texas are significantly less likely to be in a medical home than CSHCN in high performing states.
- Out of the 4 states that were interviewed, no state had an official policy that explicitly outlines how transition services should be delivered in the state.
- Only the highest performing state (Kansas) had a centralized place where transition tools were located, all other states interviewed did not have a central area.

Recommendations:

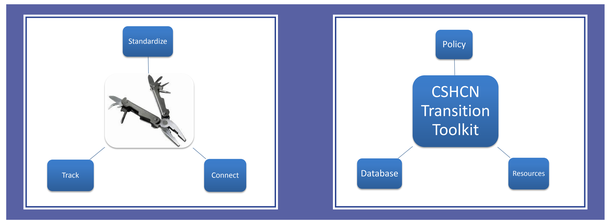
- Create a policy that explicitly outlines how transition for CSHCN should be addressed by all providers. This policy will ensure that future transition services are standardized and that providers understand what is expected for the provision of adequate transition services to CSHCN. Texas' provision of transition services can be improved by increasing the amount of CSHCN who have a medical home.
- Conducting routine evaluations of existing programs will allow officials to discern the efficacy of transition programs. Evaluation is important to ensure that the programs are actually addressing the needs of CSHCN.

CSHCN Prevalence and Transition[3]



Project Description

The CSHCN Services Program began the development of Transition Toolkit for health care benefit clients based upon best practices to help improve outcomes for transitioning youth and to ensure that supports and services are in place to facilitate a successful move to adult health care, work, and independent living. A workgroup was formed consisting of central office program and policy staff and regional social workers who provide case management to our client populations. The workgroup began meeting regularly in January 2013 and utilizing a lifecourse framework, focused on the development of a transition policy, resource collection and the development of a database.



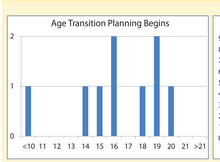
Selected Results

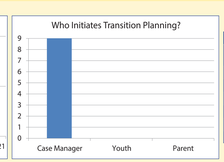
Survey:

A survey was conducted of workgroup members to gauge current attitudes and practices regarding transition.

Survey Questions:

- As a case manager, what does transition to adulthood mean to you and to the children and families you serve? What role do you play as a case manager to a transitioning youth and his/her family?
- At what age does transition planning usually begin, in your experience?
- What is the biggest challenge you face as a case manager in successfully preparing a youth with special needs for adulthood?
- What are parents' main concerns with regard to their child's transition?
- What are some resources you utilize to help you prepare your clients and their families for transition?
- What is the most requested form of assistance by youth and/or parents with regard to transition?
- Who usually initiates transition planning: you, the youth, a parent/guardian, or someone else?
- Please indicate your familiarity with the following tools: transition policy, transition plan, emergency/disaster plan, portable medical summary, assessment/checklist, CSHCN transition resource brochure, CSHCN CM transition letter template.
- When asked what transition to adulthood means and what is their role as a case manager in the process, respondents indicated information, referral, education, resources, medical home and services.
- The biggest challenges they identified in preparing youth for adulthood was lack of resources, lack of services and financial limitations.
- Parental concerns included lack of resources and lack/loss of services.





Transition Tools	Familiarity/Use
Transition Policy	Familiar/Use [3] Not Familiar/Will Consider [3]
Transition Plan	Familiar/Use [5]
Emergency/Disaster Plan	Familiar/Use [7]
Portable Medical Summary	Not Familiar/Will Consider [4]
Assessments/Checklists	Familiar/Use [5]
CSHCNTransition Brochure	Not Familiar/Will Consider [4]
CSHCNLetter Template	Not Familiar/Will Consider [4]

Resources Utilized to Facilitate Transition

- Referral to other agencies
- Community medical centers
- CSHCN website
- Referral to schools, ESCs
- Referral to private partners
- Information specific to their needs

Most Requested Form of Assistance

- Adult services for unfunded clients
- Health insurance
- SSI
- Medicaid waivers
- Guardianship
- Respite
- Vocational training
- Attendant services
- CBA
- Case management
- Independent living

Policy Development:

- Purpose

The Purchased Health Services Unit is dedicated to providing our transitioning CSCHN Services Program clients with tools and resources to allow them, and their caretakers, to establish a smooth transition to adulthood with medical, social, educational, employment and independent living supports in place.

- Definitions

Transitioning Client -- A child or youth with a special health care need who, at age 21, is no longer eligible for CSHCN Services Program services.

Transitioning Client with Cystic Fibrosis -- A CSHCN Services Program client with Cystic Fibrosis (CF) is eligible for transition services as long as they remain on the Program.

Transition Services -- Resources provided through a coordinated set of activities for clients and their families that are tailored to the needs, goals, preferences, interests and strengths of the client. Transition services offered are unique to the developmental considerations of the client.

- Stages of Transition

Stage 1	0-3 years old	Stage 4	11-14 years old
Stage 2	3-5 years old	Stage 5	14-18 years old
Stage 3	5-11 years old	Stage 6	18-21 years old

Resources:

The workgroup began gathering resources and sharing them on a Sharepoint site for the following:

- Child/Youth
- Parent/Guardian
- Providers

Categories of Resources:

- Vocational
- Education
- Social
- Health and Safety
- Housing
- Financial
- Medical
- Transportation
- Legal

Development of Resources

Started with Stage 6 (18-21 years old) health care benefit clients.

Database:

- Components Identified:
  - Client's birth date and age
  - Diagnosis
  - Date they were last provided with transition care
  - Client's location
  - Parents' name and phone
  - Physicians
  - Referrals

Barriers

- Our goal was to have representation from each of Texas' Health Service Regions (HSR) on the workgroup. We were able to recruit workgroup members from all but one of the HSR in Texas, HSR 6/5S. This region covers the Houston area and represents a large population of CSHCN.
- Participation and engagement of regional staff members began to wane.
- Utilizing the lifecourse approach, staff found that there is a paucity of resources for **Stages 1-3** of the toolkit. In addition, there is a lack of resources that can be utilized for noncitizens.
- While elements of the database have been identified, we are still in discussion on integrating the database into a new consolidated data management system.

Lessons Learned

- We needed to recruit various stakeholders including family members and professionals earlier in the process.
- With the waning participation of workgroup members, we should also obtain commitment from participants to be engaged members and ensure routine contribution.
- We should have engaged and updated regional managers whose staff are participating in the workgroup on a more regular basis and provided them with feedback of their staff's participation.
- We should have secured a commitment regarding the database home and features.

Next Steps

After identifying barriers and lessons learned from the project, the transition toolkit workgroup was dissolved and the project was moved under the Texas Title V Transition Workgroup. The Workgroup is currently undertaking a quality improvement project to identify a strategic mission and implementation plan to improve participation in the Workgroup and refinement/utilization of resources. A final meeting of the original toolkit workgroup was held in March, 2014, and participants were asked to reaffirm their commitment to the project. Three original members have expressed interest in continued participation and we have recruited 15 members to participate in the new workgroup.

This workgroup includes diverse stakeholders such as parents, professionals, program and other state agency staff. Policy development is ongoing and resources continue to be collected and refined. Finally, work continues in developing business requirements for the database and we are trying to secure a final home for the system. Clients are currently being identified by transition stage on a monthly regional list for case managers.

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4. American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine, A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs, Pediatrics 2002; 110; 1304.
5. Factors Associated with Texas' Performance on Delivery of Transition Services to Children with Special Health Care Needs (CSHCN), Florence Kanu, MPH candidate 2014.